



# **National Action Plan for Bone Health: Recommendations from the Summit for a National Action Plan for Bone Health**

*National Coalition for Osteoporosis and Related Bone Diseases*







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## Preface

In June 2008, more than 150 individuals representing an array of stakeholders concerned about bone health met in Washington, DC, to develop an action plan and agenda to advance bone health promotion and disease prevention. The National Coalition for Osteoporosis and Related Bone Diseases, which includes the American Society for Bone and Mineral Research, National Osteoporosis Foundation, Osteogenesis Imperfecta Foundation, and the Paget Foundation, convened the meeting. Meeting participants built on the findings and recommendations of the 2004 Surgeon General's Report on Bone Health and Osteoporosis and on lessons learned from the development and implementation of the European Action Plan for Osteoporosis. Participants also discussed current bone health activities and initiatives and they considered the latest scientific advances, policy concerns and findings regarding bone health awareness, education and practice. The discussions generated numerous concerns, ideas, and suggestions, which participants used to devise recommended steps for advancing bone health in our nation. This National Action Plan for Bone Health is a direct result of their work and is a testament to the widespread commitment to making the issues and importance of bone health a national health priority.



# 1

## Background

### The Importance of Bone Health

Bone plays an important structural role in the body. It provides mobility, support, and protection for the body, and acts as a storehouse for essential minerals. Bone is not static, even in fully grown adults. Instead, it is a living organ that goes through a process of removal and replacement throughout life: –most of the adult skeleton is replaced about every 10 years.<sup>1</sup> Healthy bones are critical to overall health, and behaviors that promote health and disease prevention also are key to maintaining a strong and healthy skeleton. These behaviors include, for example, getting regular exercise, eating a balanced diet, not smoking, preventing falls and injuries, and drinking alcohol only in moderation.

Promoting bone health is important in helping to stem the rate and risk of osteoporosis, the most common bone disease, which currently afflicts 10 million Americans over the age of 50.<sup>2</sup> Osteoporosis is characterized by a loss of bone mass, resulting in greater bone fragility, which increases the risk of bone breakage, also known as fracture. The fractures most commonly associated with osteoporosis occur in the hip or spine, and often result in a downward spiral in physical and mental health, which can greatly impair quality of life and can result in death. Indeed, 20 percent of older adults who suffer a hip fracture die within 1 year.<sup>3</sup>

Although osteoporosis typically manifests itself later in life, the roots of the disease may stretch back to early childhood and reflect a lifetime of risks and behaviors. Peak bone growth and development occur in infancy and teen years. Peak bone mass is typically obtained by the late twenties and begins to decline after age 35. Thus, behaviors to promote bone health and reduce bone loss need to be understood and applied at every age. In addition, the early identification and screening of individuals at increased risk for osteoporosis is critical for the opportunities it offers to apply preventive measures that can boost bone health and decrease the risk of fractures.

Although osteoporosis is a “silent disease” before fractures occur, the effects of fragility fractures are profound, not only for their immediate morbidity and mortality, but also because they reduce patients’ quality of life.<sup>4</sup> Fractures have a negative effect on the standard measure, quality – adjusted life years (QALY); this effect increases progressively both with age and with number of fractures. Conversely, treatment of osteoporosis can improve QALY by reducing fracture risk in a cost effective manner.<sup>5</sup>

#### Bone Health Basics

**Osteoporosis**, or porous bone, is a disease characterized by low bone mass; greater bone fragility; and higher risk of broken bones, also known as **fractures**, especially of the hip, spine, and wrist

**Paget’s disease** is a bone disease that causes skeletal deformities and fractures

**Osteogenesis imperfecta** is an inherited disorder that causes brittle bones and frequent bone fractures in childhood

**Many other diseases**, such as cancer, arthritis, and HIV/AIDS, and their treatment, can have adverse effects on bone health

**A hip fracture** almost always requires hospitalization and major surgery. It can impair a person’s ability to walk unassisted and may cause prolonged or permanent disability or even death.

**Spinal or vertebral fractures** also have serious consequences, including loss of height, severe back pain, and deformity.

***“Our understanding of bone health has benefitted greatly from our scrutiny of what goes wrong in the cases of rare bone diseases.”***

—Physician, Researcher

***“The challenge in osteoporosis is that it is often a silent disease, unlike myocardial infarction, which is more obvious. Osteoporosis can lead to mortality and morbidity, but it is not seen as such.”***

—Patient Advocate

Other bone diseases affect the lives of many Americans and their families. Nearly 1.5 million people in the United States may have Paget’s disease, the second most common bone disease.<sup>6</sup> Paget’s disease is characterized by pain, skeletal deformities, increased risk for multiple fractures, and other complications such as hearing loss. Osteogenesis imperfecta is a genetic disorder that causes brittle bones that break easily. Estimates of the numbers of individuals in the United States with this disorder range from 25,000 to 50,000 – exact numbers are difficult to calculate because milder forms of the disease may go undetected.<sup>7</sup> Although these, and other rare bone diseases, may affect fewer individuals than other conditions, their importance is far reaching: the research conducted to more fully understand these diseases has significantly advanced the science of bone health and increased our potential to address bone loss, fragility, or disease.

## **Magnitude and Urgency**

The magnitude of the importance of bone health is already far greater than is widely recognized. An estimated 1.5 million people suffer an osteoporosis-related fracture each year, and over their life times, half of all women and one-quarter of all men can expect to join their ranks.<sup>8</sup> Among people age 65 and older, unintentional falls account for 87% of all fractures treated in emergency departments.<sup>9</sup>

The economic costs of bone diseases, including medical care and lost productivity, are substantial. For example, the total annual bill for osteoporotic fractures alone is estimated to be \$30 billion.<sup>10,11</sup> Added to this are the enormous personal and social tolls of bone diseases and their associated fractures or disability.

The lower incidence of osteoporosis and fragility fractures in African Americans has led to a lack of attention to bone health in this population.<sup>12</sup> Even with an incidence that is half that of white women, a substantial number of African American women are at risk for fragility fractures.<sup>13</sup> The fact that 10 percent or more of African American women are likely to have a fragility fracture after the age of 50 is more than sufficient to warrant increased attention to diagnosis and therapy.

With the aging of the Baby Boomers, the urgency for action to improve bone health will only increase. Thus, the time for action is now. The impact of bone disease is too great to ignore, as is the potential for reducing the risks and consequences of these diseases and improving the health of our nation.

## **Progress and Promise**

Continued advances in screening, risk assessment, prevention, and treatment offer unprecedented opportunities to improve bone health. However, the promises of those advances are being compromised by the challenges of inertia, demographic and policy pressures, and a lack of public and social recognition of the urgent need.

The rate of scientific and clinical advances in bone health is remarkable. Medications now exist that can treat, prevent, and reverse the effects of many bone diseases. Once seen as an inevitable part of aging, osteoporosis has become a chronic condition that can be largely prevented and effectively treated.

New tools enable clinicians to assess the risk of osteoporosis, screen patients for the disease quickly, and refer them for treatment or targeted prevention measures. For example, the World Health Organization (WHO) recently developed and released a new online fracture risk assessment tool called FRAX®, which gives clinicians a quick and easy way to measure patients' 10 year fracture risk. In addition, dual x-ray energy absorptiometry testing (DXA) has become the gold standard for measuring bone density, diagnosing osteoporosis and following changes in bone density over time.

New pharmaceutical developments include monthly and annual doses of bone strengthening drugs, which encourages patients' adherence to treatment. Recently developed drugs help the body build new bone, and new antiresorptives prevent or reduce the bone loss cycle.

Scientific advances have provided a better understanding of bone diagnoses and treatment. For example, genetic research has revealed the role of critical genes in particular bone diseases. Other advancements include a better understanding of factors such as the roles of different bone cells and of factors such as osteocytes and osteoblasts, Wnt signaling and RANKL/RANK in the formation, growth, maturation, and break down of bones. In addition, new evidence points to calcium and vitamin D's crucial roles in promoting and maintaining bone health. In addition, physical activity is now known to play a critical role in building healthy bones and possibly preventing some bone diseases. And fall prevention remains a cornerstone of many programs seeking to reduce low-impact fractures.





## 2 Building Consensus for a National Focus on Bone Health

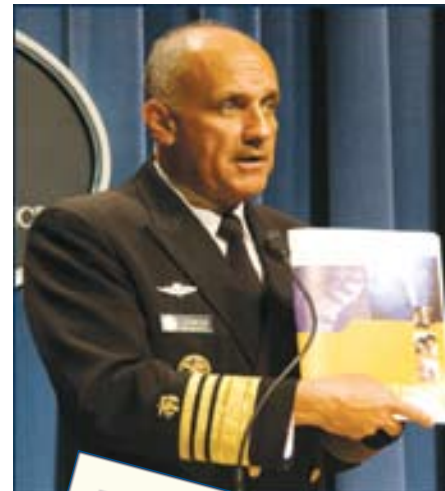
### Building on the Surgeon General's Vision for the Future

Much remains to be done to advance bone health and prevent and treat bone disease. The 2004 publication of *Bone Health and Osteoporosis: A Report of the Surgeon General*<sup>14</sup> created hopes and expectations for almost immediate advances, especially in terms of public and clinician awareness and understanding of bone health. The report was aimed at bridging the gap between the knowledge base and the practice regarding the prevention of bone disease and promotion of bone health – to apply cutting-edge research findings to actual clinical practice. It also called for greater recognition of the importance of bone health to general health and well-being.

*Bone Health and Osteoporosis: A Report of the Surgeon General* specifically recommended increasing public and professional awareness of bone health and the effectiveness of prevention and treatment. It called for greater integration of bone health with other health prevention issues and initiatives. The report also called for of fragility fractures to be recognized as sentinel events for the diagnosis and treatment of osteoporosis, and underscored a need to change the paradigm of prevention and treatment by treating fragility fractures as “red flags” signaling potential bone disease. The Surgeon General’s report emphasized that meeting these recommendations would require the participation of and collaboration among multiple stakeholders and systems (e.g., health care providers, scientific researchers, patients, advocates, policy makers, and health organizations).

One of the key conclusions of the Surgeon General’s report was: “More than enough is known today to get started on any of a variety of critical actions that are needed to enhance the bone health status of Americans.”

Unfortunately, the call and challenge of the 2004 *Bone Health and Osteoporosis: A Report of the Surgeon General* has not been heeded.



***“...More than enough is known today to get started on any of a variety of critical actions that are needed to enhance the bone health status of Americans.”***

—Surgeon General’s Report on Bone Health and Osteoporosis, 2004

***“You are never too old or too young to improve your bone health.”***

—Richard Carmona, M.D.  
Former Surgeon General

Although there have been many federal, state, and professional and voluntary association efforts to increase awareness of bone health and bone diseases, their efforts have been diffuse and their reach has been minimal. They have suffered from the lack of a major, coordinated national effort to promote bone health and the recommendations of the Surgeon General’s report. The results are telling:

- Surveys of clinicians and patients indicate that bone health awareness has **not** increased<sup>15</sup>
- The connections among bone health, healthy eating and physical activity, and preventing falls and injury have not been successfully integrated with other major health campaigns, such as those designed to stem rising obesity rates or prevent heart disease and diabetes
- Findings from the national Healthcare Effectiveness Data and Information Set (HEDIS) suggest that follow-up treatment for osteoporotic fractures has changed very little, indicating that physicians are no more likely than they were 4 years ago to treat low-impact fractures as sentinel events<sup>16,17</sup>
- DXA remains under-utilized; the International Society for Clinical Densitometry estimates that currently, only 13 percent of eligible Medicare beneficiaries receive DXA testing<sup>8</sup>

## **Challenges Facing Bone Health Advocates**

One of the persistent challenges facing bone health advocates and efforts is the stigma associated with aging, frailty, and deformity. In our youth-obsessed culture, osteoporosis and other bone diseases call forth negative images of fragility, dependence, and disability. Older women themselves are reluctant to admit or acknowledge that they are suffering from an “old person’s disease.” Moreover, the general public does not understand that bone health spans every age and ethnic group, and that men and women are both at risk for developing bone diseases. Indeed, the rates of fatal hip fractures in men are on the rise: increasing by 10 percent from 2000 to 2003.<sup>19</sup> Although osteoporosis is not a geriatric disease, it may be seen as the geriatric consequence of a full life’s worth of health predictors and behaviors, risks and choices; still, that message is not widely understood. Most individuals continue to perceive osteoporosis as a disease of elderly white women when in fact, men, younger persons, and people of color also can develop osteoporosis and other bone diseases. Even more importantly, people do not understand that preventive measures and healthy behaviors early in life and through adulthood can have a significant effect on bone health in later life.

New challenges have arisen since the publication of the Surgeon General’s report. Foremost among these are legislative reductions to Medicare reimbursement rates to physicians for DXA screening, which threaten to counter key advancements in the detection, assessment, and ultimately treatment of osteoporosis. The national average for the Medicare reimbursement of DXA to physicians was reduced from \$139 in 2006 to \$82 in 2007, with further cuts planned through 2010.<sup>20, 21</sup> Current estimates suggest that the average cost of performing a DXA scan is \$134, thus the reimbursement rate will be far below the break-even point for physicians – serving as a strong disincentive for them to continue offering this test.<sup>22</sup>

The promotion of prevention and treatment measures for individuals with osteoporosis, Paget's disease, or low bone mass also suffered a setback with the widespread media coverage of possible associations between the use of bisphosphonates commonly used to inhibit bone loss in individuals with or at risk of bone disease, and a condition called osteonecrosis of the jaw (ONJ). ONJ involves the exposure of the bone of the upper or lower jaw due to dental extraction or trauma, causing a painful wound that does not heal. More than 90% of cases of ONJ occur in patients who have been given multiple doses of intravenous bisphosphonates to prevent or treat bone metastases. An ASBMR task force reviewed available information and estimated that the risk of ONJ associated with bisphosphonate treatment for osteoporosis is low, between 1 to 10 per 100,000 patient treatment years.<sup>23</sup> The risk of ONJ in cancer patients treated with high doses of intravenous bisphosphonates is much higher, in the range of 1 to 10 per 100 patients. Although the risk of ONJ with bisphosphonate use in osteoporosis is very low, the perceived risk is high due to media attention. As a result, the rate of bisphosphonate prescriptions and use has dropped, and many dentists no longer treat patients who are taking bisphosphonates. Balanced information on this problem is essential so that the benefits of therapy will not be denied to patients at risk for fractures.

Recent research regarding rates of vitamin D insufficiency indicates a challenge and an opportunity. Evidence shows that in the United States and around the world, vitamin D insufficiency may be one of the most commonly unrecognized medical conditions – one that exposes individuals to a greater risk of bone disease and fracture due to the critical connection between vitamin D and the body's ability to absorb calcium and phosphorus.<sup>24</sup> These findings present an opportunity to revisit the recommendations regarding vitamin D intake or supplementation and explore strategies for increasing daily intake.

***“Many people don’t realize that bone is a living organ, and not just a stick. To help people understand the importance of bone health, we need to put a human face on bone disease.”***

—Media Expert

***The general public does not understand that bone health spans every age and ethnic or racial group, and that men and women are both at risk for developing bone disease.***







# 3

## Developing a National Action Plan for Bone Health

### Assessing Progress and Charting a Course

In 2008, the National Coalition for Osteoporosis and Related Bone Diseases (also known as the ‘Bone Coalition’) commissioned several studies, including an environmental scan and a literature review, to assess progress made toward reaching the goals of the 2004 Surgeon General’s report. In interviews with 24 opinion leaders, the study found that while progress had been made in building the science base, much less had been accomplished in terms of increasing awareness, integrating messages, or changing paradigms.

#### Environmental Scan Key Findings

##### Positive achievements included the following:

- Development of pharmaceuticals to maintain or increase bone density
- Use of DXA screening
- Advances in the assessment of risk factors, such as development of the FRAX® tool
- Increased recognition of the importance of vitamin D in promoting bone health
- Greater understanding of the factors regulating bone cells and development of monoclonal antibody therapy

##### Negative findings included the following:

- Little has been done to change the treatment paradigm
- Public education programs have been inadequate in raising public awareness
- Health care professionals receive inadequate training about bone health
- Little has been done to integrate messages about bone health with broader messages about the importance of healthy lifestyles in preventing an array of chronic disease problems

#### National Coalition for Osteoporosis and Related Bone Diseases

- American Society for Bone and Mineral Research
- National Osteoporosis Foundation
- Osteogenesis Imperfecta Foundation
- The Paget Foundation



## Summit for a National Action Plan for Bone Health

Based on these findings, and a consensus that the field needed guidance and focus to direct its efforts, the National Coalition for Osteoporosis and Related Bone Diseases sponsored a 2-day summit in June 2008, in Washington, DC. This meeting was designed to:

- Develop a national action plan to increase awareness among professionals and the public about prevention, diagnosis, and treatment of osteoporosis and other bone diseases
- Establish priorities for policies and programs for health care providers, health systems, and population-based approaches
- Engage key stakeholders in partnerships to advance action
- Initiate long-term implementation and evaluation efforts coordinated by a planning group of public and private organizations

The summit brought together approximately 150 representatives of major stakeholder groups, including those from research and academia, professional and voluntary health organizations, trade organizations, industry, and government, to discuss strategies and ideas to create a national action plan to advance the Surgeon General's goals.

Stakeholders met in small, facilitator-led workgroups to propose and discuss key strategies and activities that would serve as the underpinnings of a National Action Plan for Bone Health. Stakeholders first met in groups focused on issues specific to the action steps outlined by the Surgeon General's report (e.g., increasing awareness, building the science base, changing the paradigm, integrating health messages). Using strategies developed during these work sessions, stakeholders met to discuss how their particular fields or disciplines (e.g., voluntary health organizations, professionals, government) could implement or advance those strategies. The following action plan is a distillation of these recommendations and ideas, with a particular focus on the themes that emerged as the most overarching and most pressing.



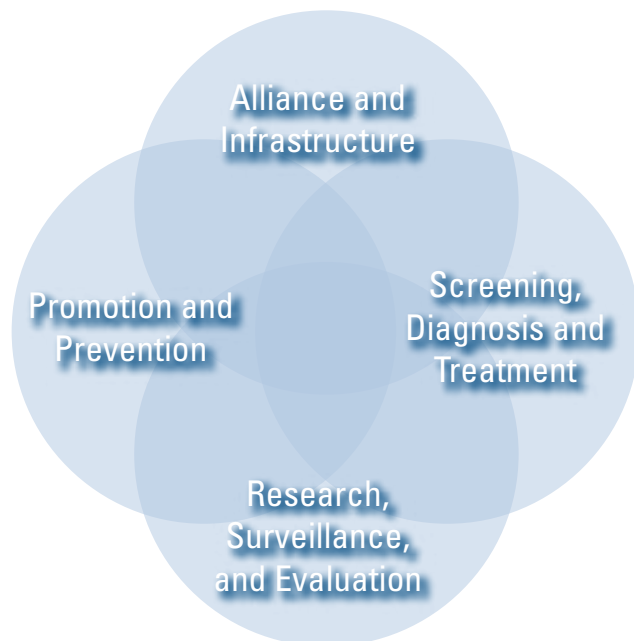
# 4

## A National Action Plan for Bone Health: Recommended Strategies

Summit participants condensed dozens of ideas into specific steps for improving the nation's bone health. For the action plan, the recommendations were grouped into four priority areas:

- 1. Develop a bone health alliance**
- 2. Promote bone health and prevent disease**
- 3. Improve diagnosis and treatment**
- 4. Enhance research, surveillance, and evaluation**

Each of these four priority areas includes several action steps to be taken by the bone health community. Next steps for the action plan include seeking more input and guidance from stakeholder groups, with a focus on determining more specifically how to accomplish these steps and who will take responsibility for doing so. The following section focuses on key recommendations that emerged across all 14 workgroup sessions and provides the context in which the recommendations were made.



## Priority One: Develop A Bone Health Alliance

A collaborative, ongoing infrastructure is needed to change the paradigm – to increase awareness of bone health among the public and professionals, treat fractures as part of the continuum of bone health and disease, and develop prevention and treatment approaches. This effort also must include a focus by the bone health community on integrating health education messages about healthy lifestyles at two levels: (1) bone health organizations themselves should consider integrating messages so that they are uniform and consistent, *and* (2) bone health organizations should work with other chronic disease agencies and nonprofit organizations to support linked messages focused on healthy lifestyle choices.



Strategy	Action Steps	Stakeholders
Forge a national alliance focused on bone health issues	Create an organizational structure and continue momentum from the Summit forward	■ All stakeholders involved in the Bone Health Coalition
	Work with existing federally focused clearinghouse to coordinate government and nongovernmental bone health-related information	
	Develop social marketing for bone health messages	
Collaborate with organizations whose messages about healthy lifestyles dovetail with messages about improving bone health	Highlight successful programs	■ Representatives from other chronic condition organizations with leaders of bone health advocacy, consumers, and professional organizations
	Agree on key set of messages about benefits to bone health of nutrition, exercise and fall prevention	
	Develop integrated and coordinated messages and programs	

### *Forge a national alliance focused on bone health issues.*

A national Alliance for bone health, with a shared mission and vision for promoting bone health issues, should be formed. Such an Alliance is essential to integrating, focusing, and promoting an array of relevant issues and concerns. Key steps to forging this Alliance include determining where it would be housed among existing bone health organizations and identifying and recruiting key stakeholder organizations. The organization would need to develop a charter and set the course for shared priorities, which would primarily focus on implementing the National Action Plan.

Once the structure has been created, the Alliance could be charged with carrying the momentum of the Summit for a National Action Plan for Bone Health forward by:

- Sponsoring advocacy activities, capitalizing on issues around which there is consensus, and advancing policy and legislation to encourage and promote bone health
- Providing leadership in areas around which organizations share common interests and goals, such as spearheading efforts to address declining levels of DXA reimbursement or concerns about appropriate levels of vitamin D intake



- Developing bone health education messages for social marketing campaigns, such as those that focus on healthy lifestyle choices and injury prevention
- Keeping bone health issues at the forefront of the mission and vision of all bone health organizations by sponsoring joint sessions, conferences, and events to coincide with the annual meetings of professional organizations such as the American Society for Bone and Mineral Research, the American Academy of Orthopaedic Surgeons, the American Orthopaedic Association, the American Association of Clinical Endocrinologists, and the American College of Rheumatology

The Alliance also could coordinate with the existing federal bone health clearinghouse — the NIH Osteoporosis and Related Bone Disease~National Resource Center — to provide online and print information from a range of governmental and nongovernmental organizations to professionals and to the public, to track and evaluate programs and policies, to call for research funding, and to advocate for change and improvement in public policy. More could be done to track state, local, and private programs devoted to bone health, and to link health care consumers to resources and information.

Finally, the Alliance could focus attention on social marketing for bone health messages, first by inventorying existing programs and their effect, and then by developing and evaluating new messages and programs. Many organizations and agencies now promote programs about bone health, with messages that target not only women at high risk but also children, teens, men, people of color, and disadvantaged populations. Examples of these programs include the U.S. Bone and Joint Decade's *Fit to a T* campaign, which educates people about the importance of knowing their T-score and the Office on Women's Health *Powerful Bones—Powerful Girls* campaign, which targets young girls with messages about physical activity, nutrition, and bone health. Many State and local injury prevention programs include a focus on fall prevention for older adults, in part to stem the rate of low-impact fractures.<sup>26</sup>

Lessons could be learned from the successes of other public health information and awareness campaigns such as those that have reduced smoking or promoted traffic safety. Any campaign developed would need to target multiple audiences with an array of needs — a range of strategies and materials would need to reflect the continuum on which people need bone health information, targeting all ages and all phases of bone health. These programs would necessarily reflect cultural and gender issues in development of messages and materials.

### ***Collaborate with organizations whose messages about healthy lifestyles dovetail with messages about improving bone health.***

Many disease-based organizations share with bone health a focus on healthy lifestyle messages around good nutrition and exercise as well as injury prevention. To date, however, the bone health community has not worked effectively to integrate its messages of good nutrition, physical activity, and fall prevention with more overarching messages that promote healthy lifestyles in general. Such collaboration and integration may be a particularly effective way to educate populations that may not see themselves at risk — men, younger persons, and people of color — as well as the providers with whom they interact.

Bone health organizations should first look at existing programs and campaigns that promote similar messages (e.g., programs on obesity prevention, diabetes prevention

***Lessons could be learned from the successes of other public health information and awareness campaigns, such as those that have reduced smoking or promoted the use of seatbelts and bicycle helmets.***

***“There is a serious gap between what we know we can and should do and what we are doing in the community.”***

—Physician, Researcher



and treatment, cardiovascular health) to find common ground around which to build campaigns and messages. Creating an inventory of existing or successful programs and their sponsors, both federal and private, is essential. This inventory could form the basis for a database or listing of messages most prevalent in media and educational materials. The process would examine successful programs, especially those that have been evaluated for effectiveness.

An interdisciplinary medical advisory group could also be convened to agree on a key set of messages about nutrition and exercise benefits for bone health. From here, effective messages for an array of audiences could be developed and implemented. This inventory should include a look at direct-to-consumer advertising for bone health products, and how those products are marketed and positioned to consumers and health care professionals. Such messages should begin with clear hooks, such as information about vitamin D insufficiency and adequate intake or injury and fall prevention, to engage and inform the public and providers. These messages could then be promoted by the proposed national Alliance, by individual bone health organizations and by other organizations with an interest in disease prevention and health promotion.

The national Alliance would aim to foster connections to other chronic disease and professional organizations with which it would share common messages about prevention, treatment, and diagnosis; and to work with these organizations to forge integrated and coordinated messages and programs about healthy lifestyles. The Alliance could work closely with organizations such as the National Association of Chronic Disease Directors (NACDD), which has advocacy and education programs focused on osteoporosis.

## Priority Two: Promote Bone Health And Prevent Disease

Developing and maintaining strong, healthy bones is a lifelong process, one that begins at birth and continues throughout the lifespan. Adults and children alike benefit from nutrition and exercise that promote bone health and growth. As noted by the Surgeon General, individuals and families play a role in understanding and promoting bone health, not only for their children, but for their middle-aged and aging parents. Health care providers and other key stakeholders also must play a critical role in promoting bone health and preventing bone disease.

Strategy	Action Steps	Stakeholders
Build capacity of health care providers to focus on bone health across the lifespan	Work with leadership of medical organizations to develop and implement behavior change strategies within primary care, emergency departments, and orthopedic practices	<ul style="list-style-type: none"> <li>■ Leaders at schools of medicine and nursing, as well as allied health professional educational programs</li> <li>■ Professional societies</li> <li>■ Health care professionals</li> </ul>
Promote adequate vitamin D and calcium intake, with a focus on revising the adequate intake level for vitamin D	Support current efforts	<ul style="list-style-type: none"> <li>■ Bone health experts</li> <li>■ Researchers and scientists academicians</li> <li>■ Professional and voluntary organizations</li> <li>■ Policymakers</li> </ul>
	Enhance patient education	
	Develop consistent messages	
	Re-evaluate vitamin D requirements	
Increase advocacy activities at the federal and state levels	Review and revise model state legislation	<ul style="list-style-type: none"> <li>■ Consumer and voluntary health organizations</li> <li>■ Professional societies and organizations</li> <li>■ Health care professionals</li> <li>■ Policymakers</li> </ul>
	Coordinate with other organizations to conduct “Capitol Hill Days”	
	Focus advocacy efforts on topics where there is consensus in the bone health community	
Develop standards or guidelines of care and performance measures	Inventory existing standards and guidelines	<ul style="list-style-type: none"> <li>■ Professional organizations</li> <li>■ Health care purchasers/insurers</li> <li>■ Federal agencies</li> </ul>
	Develop national consensus	
	Develop and implement mechanisms for monitoring use of standards and guidelines	



### ***Build capacity of health care providers to focus on bone health across the lifespan.***

Although individuals are responsible for making lifestyle changes, all health care professionals – from pediatricians to geriatricians and everyone in between – have a part to play in working with patients to understand bone health and engage in healthy lifestyles for bone health, ranging from information about nutrition and exercise to steps individuals can take to prevent falls.

The bone health community must work with umbrella organizations and the leadership of professional associations to help ensure that:

- Primary care providers, including physicians, nurse practitioners, and physician assistants pay close attention to bone health issues and emphasize the basics of good bone health and fall prevention during interactions with patients
- Health care professionals in emergency departments and orthopedic practices recognize that many bone fractures signal the potential for metabolic bone disease and to go beyond “fixing patients’ bones” by referring them to an appropriate health care professional for further evaluation

One way to encourage health care professionals and organizations to attend to messages about bone health is to work with the Joint Commission (Joint Commission on Accreditation of Healthcare Organizations) and other organizations (such as the American Academy of Orthopaedic Surgeons, American Medical Association, American Academy of Pediatrics, and the American College of Emergency Physicians) to develop practice standards to be used during the accreditation process. These standards could, for example, require hospitals and nursing homes to view low trauma fractures as a sentinel event for treatment of osteoporosis and develop a plan of action.

### ***Promote adequate vitamin D and calcium intake, with a focus on revising the adequate intake level for vitamin D***

Adequate calcium and vitamin D intake are critical to maintaining health and preventing illnesses. Calcium plays a key role in building stronger, denser bones early in life and keeping them strong throughout the life span. Vitamin D is necessary for the absorption of calcium. Yet, findings suggest that 70 percent of Americans over age 2 do not get enough calcium on a daily basis (1,000 mg for adults under age 50, and 1,200 for those over 50).<sup>25</sup> Similarly, current research suggests that a minimum of 25 percent of adolescents and adults in the United States may not have sufficient levels of vitamin D, with higher rates of insufficiency among African Americans, the homebound, and the elderly.<sup>26, 27</sup> Emerging research points to a role for vitamin D in an array of illnesses, beyond its well-known effects on osteoporosis and bone disease; vitamin D insufficiency may play a role in depression, diabetes, certain cancers, and impaired neuromuscular function. For bone health in particular, calcium partners with vitamin D; a deficiency of either can contribute to the mechanism of bone loss.

Efforts to address this issue may include several approaches:

- Encouraging clinicians to ask patients about their daily calcium intake and to continue to test patients at risk for vitamin D insufficiency (e.g., those over the age of 50, those with limited sun exposure, those who are obese) — prescribing appropriate therapeutic doses for those with low levels



- Encouraging organizations and academic institutions to educate providers and patients about calcium and vitamin D — their roles, how to recognize deficiencies, recommended intake levels, and ways to ensure an appropriate daily intake of these nutrients
- Incorporating messages into existing programs about the importance of calcium and vitamin D and ways to ensure adequate daily intake — particularly messages targeting nutrition, obesity prevention, and healthy lifestyles (including physical activity)
- Developing consistent messaging regarding vitamin D — mixed messages and recommendations confuse the public and confound professionals. The Agency for Healthcare Research and Quality published an August 2007 evidence-based report, *Effectiveness and Safety of Vitamin D in Relation to Bone Health*<sup>28</sup>, which found that the “largest body of evidence on vitamin D status and bone health was in older adults with a lack of studies in premenopausal women and infants, children, and adolescents. The quality of randomized clinical trials (RCTs) was highest in the vitamin D efficacy trials for prevention of falls and/or fractures in older adults.”<sup>29</sup> The NIH Office of Dietary Supplements Director noted, “This independent, systematic review is timely because there are mixed messages and recommendations to consumers regarding the benefits and harms of vitamin D intake.”

The federal government is undertaking a new review of evidence, which precedes any change in recommended intakes of vitamin D, currently 400 I.U. to 600 I.U. for healthy adults over 50. The U.S. Department of Agriculture (USDA) and the National Institutes of Health (NIH) are working with the Institute of Medicine (IOM) to complete this review, which includes a panel of experts selected by the IOM. The USDA Nutrient Data Laboratory is working on projects to reanalyze the amount of vitamin D in foods and beverages.

### **Increase advocacy activities at the federal and state levels.**

The public and professionals need to advocate for better screening, detection, and treatment and for public policy that promotes the importance of bone health. Advocacy efforts can encompass many activities, from urging state and federal lawmakers to enact legislation and develop public policy, to raising public awareness of bone health.

Specifically, model state legislation should be reviewed and revised so that states could enact legislation that addresses priority issues such as the need for insurers and Medicare to cover the costs of effective, evidence-based treatments. A variety of promising models exist. Many states have laws and regulations that address particular bone health issues. A 2008 inventory of state osteoporosis activities reported that 35 states and Puerto Rico have enacted laws related to osteoporosis. The majority establish statewide education, public awareness, and prevention programs. Fourteen states mandate insurance coverage for osteoporosis-related diagnostic and treatment services.<sup>30</sup>

Providers, patients and families can be galvanized to advocate for better care through membership organization-sponsored collaborative “Capitol Hill Days.” Many nonprofit health groups bring volunteer members to Washington, DC, for training on how to approach their elected officials, followed by visits to Capitol Hill. Organizations should collaborate and coordinate with one another to leverage their resources and efforts for these activities. They also can organize similar activities to promote bone health legislative action at the state level.

### **Recent State Laws**

**A 2006 Arizona bill** made grant appropriations for services related to osteoporosis, including an effort to foster collaboration among interested organizations to create a statewide network for conducting osteoporosis screenings, with a special focus on rural and underserved areas

**A 2006 Kentucky bill** established a multigenerational prevention and education program that includes a focus on educating health care professionals about national clinical guidelines

**A 2005 Maine bill** provided prescription drug benefits under the elderly low-cost drug program to include the coverage of drugs to treat osteoporosis

To maximize efforts, advocates should capitalize on topics around which there is consensus in the bone health community, such as:

- Revising guidelines for calcium and vitamin D supplementation
- Promoting adequate reimbursement rates for evidence-based tests, such as restoring DXA reimbursement rates
- Increasing funding for basic and clinical research
- Increasing focus on training health care professionals in the basics of bone health and how it relates to their practice or discipline
- Increasing awareness that bone health is a public health issue
- Promoting awareness of the role of falls in fractures and understanding of how to prevent unintentional falls and injuries
- Creating a comprehensive national program for osteoporosis and other bone diseases within CDC to provide for control, prevention and surveillance of osteoporosis, including expanded data collection, increased evaluation programs, and increased numbers of state grants. This program should also establish bone health goals and objectives for *Healthy People 2020*. Increased funding over the next decade is necessary to meet these objectives.

Bone health organizations also should reach out to all bone health and chronic disease agencies to make bone health part of their advocacy agenda. Federal and state agencies also have a critical role to play in advocating for more interagency collaboration and coordination. These agencies need to advocate for more concerted efforts to align bone health promotion programs with those for other chronic conditions. Several states have implemented successful programs targeting osteoporosis education and bone health promotion. Kentucky, New Jersey, Michigan, and West Virginia have successfully funded programs that target education and prevention strategies. New Jersey has funded a program that provides trainers to three regional hospitals to manage “Project Healthy Bone.” The state of Michigan funds programs that provide bone density

#### Existing Guidelines For Clinical Practice

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| <ul style="list-style-type: none"> <li>■ The Agency for Health Research and Quality, a clinician’s summary guide: <i>Fracture Prevention Treatments for Postmenopausal Women with Osteoporosis</i> (<a href="http://effective-healthcare.ahrq.gov/healthInfo.cfm?infotype=sg&amp;ProcessID=8&amp;DocID=95">http://effective-healthcare.ahrq.gov/healthInfo.cfm?infotype=sg&amp;ProcessID=8&amp;DocID=95</a>)</li> <li>■ The American Association of Clinical Endocrinologists: <i>Medical Guidelines for Clinical Practice for the Prevention and Treatment of Postmenopausal Osteoporosis</i>, 2001 edition with selected updates for 2003 (<a href="http://www.aace.com/pub/pdf/guidelines/osteoporosis2001Revised.pdf">http://www.aace.com/pub/pdf/guidelines/osteoporosis2001Revised.pdf</a>)</li> <li>■ The American College of Obstetricians and Gynecologists: <i>Clinical Management Guidelines for Obstetricians and Gynecologists</i>, <a href="http://www.greenjournal.org/cgi/reprint/103/1/203">http://www.greenjournal.org/cgi/reprint/103/1/203</a></li> </ul> | <ul style="list-style-type: none"> <li>■ The American College of Physicians, <i>Screening for Osteoporosis in Men: A Clinical Practice Guideline</i> (<a href="http://www.annals.org/cgi/content/abstract/148/9/680">http://www.annals.org/cgi/content/abstract/148/9/680</a>)</li> <li>■ The National Osteoporosis Foundation: <i>Clinician’s Guide to Prevention and Treatment of Osteoporosis</i>, <a href="http://www.nof.org/professionals/Clinicians_Guide.htm">http://www.nof.org/professionals/Clinicians_Guide.htm</a></li> <li>■ The North American Menopause Society position statement: <i>Management of Osteoporosis in Postmenopausal Women</i> (<a href="http://www.menopause.org/Portals/0/Content/PDF/psosteo06.pdf">http://www.menopause.org/Portals/0/Content/PDF/psosteo06.pdf</a>)</li> </ul> |
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screening and referral for underserved, high-risk populations, as well as community education programs for self-management training, including a fall-prevention program called “A Matter of Balance.” These state programs are models to other states on how funding might be used to promote a bone health agenda.

**Develop and continuously improve standards or guidelines of care and performance measures.**

No established standard of care exists for the prevention and treatment of osteoporosis and other bone diseases. There is no medical specialty for osteoporosis. The National Osteoporosis Foundation and many physician organizations offer clinical guidelines. A recent search of the National Guideline Clearinghouse (NGC) ([www.guideline.gov](http://www.guideline.gov)) revealed 38 guidelines for osteoporosis care, ranging from diagnosing the disease in men to preventing falls among the elderly. The NGC offers a guideline synthesis, *Osteoporosis Part 1. Screening and Risk Assessment*, which compares guidelines from the American College of Obstetricians and Gynecologists, the North American Menopause Society, and the University of Michigan Health System.

Although a variety of guidelines exists, they are complex, inconsistent, and not widely used. A 2008 study from the Global Longitudinal Registry of Osteoporosis in Women reported wide regional variations in the use of bone-saving drugs.<sup>31</sup> A 2004 report reviewed 24 practice guidelines and found that screening guidelines “were lacking in uniform recommendations, that screening rates generally were low and that few interventions to improve screening rates have been studied.”<sup>32</sup> The authors noted, “Osteoporosis screening guidelines lack uniformity in their development and content.”<sup>33</sup>

Standards are needed to meld the most important quality measures with standards and guidelines that clinicians can readily follow. Such guidelines would, for example, focus on identifying a first low-impact fracture as a sentinel event signaling problems in bone health. Guidelines also could focus on helping clinicians to identify, screen, and treat patients most at risk for bone disease.

Performance measures are needed that create “carrots and sticks” for clinicians to screen and diagnose patients and to follow up with appropriate treatment and care. To this end, The Joint Commission recently released a series of voluntary measures for health care organizations to use to promote and improve bone health. The measures aim to increase “the rates by which osteoporosis is diagnosed and treated, and to decrease

**American Medical Association and National Committee for Quality Assurance Physician Performance Measurement Set for Osteoporosis**

- Post fracture communication with the physician
- Managing on-going post-fracture care
- Increased screening or therapy for women aged 65 years and older
- Improved management following a fracture
- Increased use of pharmacologic therapy for osteoporosis
- Increased counseling for vitamin D and calcium intake and exercise
- More screening for the use of glucocorticosteroids and other secondary causes of osteoporosis

Joint Commission Voluntary Measures to Promote and Improve Bone Health	
1. Screening for females at risk (patients aged 60–64 with one or more risk factors, or patients over age 64 who have had at least one DXA performed)	5. Pharmacotherapy for osteoporosis
2. Screening for secondary causes of osteoporosis	6. Risk assessment and treatment for patients over age 49 who have had a fracture, in acute care settings
3. Bone mineral density (BMD) testing for patients at high risk of fracture due to glucocorticoid administration	7. Risk assessment and treatment after fracture for patients over 49 who have had a fracture, in non-acute care settings
4. Education on exercise and physical activity for osteoporosis patients	8. Smoking and alcohol education for osteoporosis and fracture patients
	9. Fall risk and personal safety education

the rates by which hip and other fragility fractures rob affected patients of their quality of life.”<sup>34</sup>

The American Medical Association (AMA) and the National Committee for Quality Assurance (NCQA) developed a physician performance measurement set for osteoporosis.<sup>35</sup> The performance measures target physicians who treat patients aged 50 and older who have an osteoporotic fracture or who manage ongoing care of a patient with osteoporosis. The six measures include improvements in post-fracture communication, follow up, and screening.



***“The problem is that different groups have different measures for different stakeholders.”***

—Physician, Researcher

Performance measures that have been developed do not appear to be in widespread use. The field must first inventory existing standards, guidelines, and performance measures to see what exists, what is being used, and what is or can be effective. Discussions then could move forward to explore a national consensus. To move from policy to practice, incentives for use of standards and performance measures should be explored and mechanisms for monitoring use and continuous adaption and improvement should be developed and implemented.

The National Committee on Quality Assurance (NCQA) uses its Health Plan Employer Data and Information Set (HEDIS) to publicly report information about health care system performance. In 2004, HEDIS included the first osteoporosis-specific performance measure for Medicare managed care plans. This measure is defined as: “The percentage of women age 67 or older who suffer a fracture who received either a BMD test or prescription treatment for osteoporosis within 6 months of the date of fracture.” In comparison to other HEDIS measures, the rates of compliance for this measure remain quite low. For instance, although 94 percent of Medicare patients receive a beta-blocker post myocardial infarction, 2006 HEDIS data report that only 22 percent of women received osteoporosis management. This rate has fluctuated slightly in recent years.<sup>36</sup> In any case, in comparison to other measures, this one remains quite low.

## Priority Three: Improve Diagnosis And Treatment

Despite significant advances in the diagnosis and assessment of bone diseases, further research is needed to improve diagnosis and treatment. More work is needed to support consumer access to important diagnostic and treatment modalities, and to support adequate reimbursement for evidence-based treatments. Provider education is an essential element of improving diagnosis and treatment. In addition, collaborative models of care, such as care management models used for other chronic conditions, are essential to improving ongoing treatment of bone disease.

Strategy	Action Steps	Stakeholders
Find better ways to diagnose disease and assess risk	Continue research to understand who is at risk and how best to initiate treatment	<ul style="list-style-type: none"> <li>■ Government researchers and academicians</li> <li>■ Clinicians</li> <li>■ Professional societies</li> <li>■ Industry researchers</li> <li>■ Experts on bone health</li> <li>■ Consumer and professional organizations and societies</li> <li>■ Policymakers</li> <li>■ Health care purchasers/insurers</li> </ul>
	Explore implementation and reaching consensus on tools (e.g., FRAX®)	
Address issues of adequate reimbursement for diagnosis and evidence-based treatments	Increase consumer understanding of access and quality issues around reimbursement rates	<ul style="list-style-type: none"> <li>■ Clinicians and health care professionals</li> <li>■ Professional societies</li> <li>■ Consumer advocacy organizations</li> <li>■ Government researchers and academicians</li> <li>■ Clinicians</li> <li>■ Professional societies</li> <li>■ Industry researchers</li> <li>■ Experts on bone health</li> <li>■ Consumer and professional organizations and societies</li> <li>■ Policymakers</li> <li>■ Health care purchasers/insurers</li> </ul>
	Seek more appropriate level of funding for reimbursement of costs to increase patient access and prevent disincentives for use	
	Support existing lobbying efforts	
Focus on fracture as a sentinel event in bone health management	Develop and implement bone health curricula	<ul style="list-style-type: none"> <li>■ Clinicians and health care professionals</li> <li>■ Professional societies</li> <li>■ Consumer advocacy organizations</li> </ul>
	Research and develop collaborative models of care (e.g., case managers, multifaceted interventions, Bone Health Teams)	





## Find better ways to diagnose disease and assess risk.

The risk factors for developing osteoporosis or other bone diseases range from genetic predisposition to lifestyle to medication and co-occurring illnesses. Early and accurate screening is essential. Diagnoses must be made sooner in the course of disease for treatment to be optimally effective. Physicians must be mindful of screening all older patients, including men and people of color, since they, too, can develop osteoporosis and Paget's disease.

Current standards that base treatment decisions largely on bone mineral density measurements are specific, but are not used to identify patients at high risk of fracture. To this end, the newly developed WHO instrument, FRAX®, represents an opportunity for physicians and others to more effectively assess a person's risk for developing osteoporosis and, based on that assessment, to refer him or her for further screening and treatment. Still under development, FRAX® needs to be matched with prevention and treatment protocols. Some opinion leaders are concerned that the way in which FRAX® was developed might affect its validity if it used in a general population. There also are some concerns that FRAX® may not be an adequate tool to assess all patients and there may need to be some limits on its use.

## Address issues of adequate reimbursement for diagnosis and evidence-based treatments.

Reimbursement rates for screening, diagnosis, and treatment practices reflect issues of patient access to care and the quality of care. Chief among these issues today is inadequate funding levels for DXA reimbursement. DXA is widely seen as the gold standard for screening and diagnosing osteoporosis. DXA of hip and spine is effective in identifying patients at increased risk for bone fracture. Although Medicare recommends screening all women at age 65 with DXA, reimbursement rates for the procedure have decreased dramatically over the past 2 years. Decreases in the DXA reimbursement rate will compromise quality of care, reduce patient access to diagnosis and care, and lead to higher costs for patients who need treatment.

The Medicare DXA reimbursement rate has been reduced by approximately 75 percent, from \$139 in 2006 to \$82 in 2007, and projected to decrease to \$56 by 2009.<sup>37</sup> Approximately 70 percent of DXA machines in the United States are in physician offices, according to the International Society for Clinical Densitometry. As a result of the decreased reimbursement for DXA, an increasing number of providers do not offer DXA screening in their offices. Opinion leaders and physicians report that a \$55 reimbursement per test will make it impossible for local physicians to cover the costs of the equipment and technical support. Many physician practices are likely to discontinue providing DXA in their offices, where it is convenient for providers and patients. A 2007 survey of 758 office-based DXA providers found that 37 percent of doctors will stop performing DXA by the end of 2007; 80 percent will cancel plans to purchase or lease new DXA equipment in 2007; 52 percent will lay off staff; and, by 2010, 93 percent will stop performing DXA studies entirely.<sup>38</sup> Consequently, DXA screening will move to the hospital setting, which will lead to challenges regarding access to care, continuity of care, and additional costs to patients. This trend will likely further reduce the already low number of Medicare beneficiaries who use this service (In 2005, 13.3 percent of beneficiaries received DXAs. In contrast 37.7 percent of 2005 beneficiaries received mammograms.<sup>39</sup>)

***Time will not wait for this issue. An aging population demands expeditious research and movement forward if we are to increase years and quality of life for all people.***

—Stephen Galson, M.D, Ph.D.  
Acting Surgeon General

In addition to adequate screening and diagnosis, there is substantial evidence that pharmacotherapy for appropriate individuals can reduce the risk of fragility fractures.<sup>40</sup> Unfortunately, evidence also shows that most individuals at risk do not receive appropriate therapy. For example, among patients who were hospitalized for low-impact fractures in 2000, only 5 percent were on pharmacologic therapy prior to admission.<sup>41</sup> While this rose to about 18 percent by 2005, when analyzed 6 months later there was only a 5 percent increase in the number of patients on treatment, and this had not improved during the 5 years. While we do not have large trials comparing different therapies, there are differences in efficacy and side-effects among available treatments.<sup>42</sup> Moreover, it is possible to monitor the response to treatment through bone density measurements and laboratory studies. The current payer systems may limit both monitoring and flexibility in the use of different therapies, particularly with the availability of a generic bisphosphonate, which payers will prefer because of its low cost. It will be important to ensure that patients have access to the treatments that are best for them.

Bone health organizations, health care providers, and the public must join advocacy efforts to ensure that appropriate reimbursement rates are set for evidence-based practices. Organizations should: increase consumer understanding of access and quality issues surrounding reimbursement rates, seek more appropriate levels of funding for reimbursement of costs to increase patient access, prevent disincentives for use, and support existing advocacy efforts. Organizations now lobbying Congress to improve DXA reimbursement include the Alliance to Protect Patient Access to Osteoporosis Testing, a partnership of the National Osteoporosis Foundation, the International Society for Clinical Densitometry, the Endocrine Society, the American Association of Clinical Endocrinologists, and the American Society for Bone and Mineral Research.

### ***Focus on fracture as a sentinel event in bone health management.***

Just as a first heart attack is now seen as a sentinel event for treating cardiovascular disease, the first fragility or low-impact fracture must be seen as an intervention opportunity. According to HEDIS data, osteoporosis management rates (20 percent in Medicare 2006) are nowhere near the intervention and treatment levels seen for other conditions, such as beta blockers administered post-myocardial infarction (93 percent) or lipid diagnosis post-cardiovascular event (81 percent).<sup>43</sup>

Engaging providers to treat a low-impact fracture as a sentinel event will require significant provider education, especially for emergency room doctors, orthopedists, and nursing home medical directors and staff, to increase awareness and understanding that such fractures are a sign that bone disease is present. In addition, hospitals, nursing homes, emergency departments, and orthopedic practices must develop mechanisms to capture patients post-fracture, as well as strategies to intervene with appropriate treatment.

One effective method may be involving a case manager to develop a treatment plan for patients who have suffered fragility fractures. The case manager model has been widely used and studied in the treatment of other chronic diseases, such as heart disease and diabetes. The case manager, often a nurse, works directly with patients and families to help them understand the disease, to develop appropriate treatment plans, and to monitor patient adherence. In one study of the effectiveness of using case managers for osteoporotic fractures, a case manager spoke with patients hospitalized for a hip fracture and arranged for BMD testing. The case manager explained the test results to



the patient and arranged for a primary care provider to prescribe medication. The study found that the case manager's involvement significantly improved rates of treatment, BMD testing, and appropriate care.<sup>44</sup>

Another study of elderly patients used wrist fracture as a sentinel event, and tested a multifaceted intervention, which included telephone-based education for patients and clinical guidelines for providers. The study found that the intervention group was more likely than the control to undergo BMD testing and to receive appropriate care.<sup>45</sup>

One proposed strategy is to develop “Bone Health Teams” composed of all health care professionals who interact with fracture patients at various stages of the continuum, from emergency department admission to discharge to rehabilitation. Such a team would monitor patients' progress, encourage BMD testing, and make appropriate treatment recommendations.

In addition, expanded provider education is needed. Bone health is not taught or structured as a distinct subject in medical schools. There is, for instance, no specialty in osteoporosis and bone disease (although some rheumatologists and endocrinologists are recognized as experts in the United States, and some centers specialize in osteoporosis treatment and management). Education for professionals needs to focus on bone health as an essential component of good health. Teaching medical and nursing students to recognize that bone health is an essential element of good health is an important addition to health education curricula. Bone health continuing education also should be included as an element for all licensing and credentialing programs, as well as for certification and recertification processes.



## Priority Four: Enhance Research, Surveillance, And Evaluation

Advances in knowledge about risk factors – combined with tools that assess the potential for bone disease in individuals – have improved the ability to identify high-risk individuals in need of further evaluation. Advances in diagnosis means that it is possible to detect bone disease early and to identify patients at highest risk. And therapeutic advances – including new classes of drugs and clinical trials confirming the value of calcium and vitamin D supplementation – have significantly reduced the risk of fractures and bone loss. However, even with optimal management, there still will be many undiagnosed patients and many fragility fractures. Thus, it is critical to continue cutting-edge research, collect and analyze data, and evaluate existing programs to highlight promising practices and translate critical findings to the field.

Strategy	Action Steps	Stakeholders
Continue and expand research now underway, and find ways to make more effective use of existing research	Conduct basic, clinical and translational research, and translating findings to the field	<ul style="list-style-type: none"> <li>■ Federal agencies charged with basic clinical and translational research</li> <li>■ Industry</li> <li>■ Policymakers who influence funding</li> <li>■ Academicians and other researchers</li> </ul>
	Conduct research to learn more about racial, socioeconomic and gender differences in bone health and disease	
Collect and analyze data to better understand who is at risk and to improve prevention, diagnosis and treatment	Identify gaps and opportunities in current data collection, reporting and evaluation	<ul style="list-style-type: none"> <li>■ Professional and voluntary health organizations that sponsor social marketing programs, in tandem with groups that evaluate and study such programs</li> <li>■ Federal agencies charged with basic clinical and translational research</li> <li>■ Industry</li> <li>■ Policymakers who influence funding</li> </ul>
	Use national surveys and other available mechanisms to collect data	
Evaluate whether existing public education programs work	Inventory and evaluate programs conducted at all levels	<ul style="list-style-type: none"> <li>■ Federal agencies</li> <li>■ Academicians and other researchers</li> </ul>
	Examine effective models used for other chronic conditions (e.g., diabetes, breast cancer, substance use, HIV/AIDS) and specific populations (e.g. people of color, men)	

***“Across NIH there is a real vibrancy of science in the area of bone health. We will continue to push forward the evidence so that others can move it into action.”***

—Government Scientist



***Continue basic research now underway and find ways to make more effective use of existing research.***

Basic scientific research has advanced treatments for bone disease, but much remains unknown or unclear. There are, for instance, gaps in our understanding of how bones work. Basic research must continue in new areas, working to understand how bone functions at a cellular level. In addition, much more translational research is needed to move the findings from basic research into clinical practice. Getting information from basic, clinical, and translational research into the hands of practitioners is essential.

Much of the current research is supported by the National Institutes of Health through the National Institute of Arthritis and Musculoskeletal and Skin Diseases and other Institutes. That research must continue as a way to develop new approaches to prevention, screening strategies, and treatments. Research at all levels – scientific research as well as clinical, translational, and pharmaceutical research – must continue. More work is needed to translate these findings and developments to the field, where they can be applied effectively to treatment and care.

There also is a need to understand how clinical research translates into the community setting. The field needs to understand better how people respond to treatment modalities, the types of medication they take and the degree to which they adhere to treatment, the factors that motivate people to seek help and treatment, and the effects that treatment has on patients' quality of life. Research also is sorely needed to learn more about racial, socioeconomic, and gender differences in bone health and disease. In addition, researchers should continue to examine and understand research being conducted in other countries.

***Collect and analyze data to better understand who is at risk and to improve prevention, diagnosis, and treatment.***

Organizations need to identify gaps and opportunities in current data collection, reporting, and evaluation. Existing data should be analyzed to find answers to ongoing questions about bone health and disease, including its prevalence and demographics. Based on this gap analysis, new questions could be formulated and incorporated into existing health surveys such as the National Health and Nutrition Examination Survey (NHANES). Questions about bone health already included in existing federal and private surveys should be re-evaluated and new questions should be developed to address emerging issues and research questions. Bone health should be included as an issue in any surveys that address related issues, such as physical activity and nutrition status, fall prevention, healthy aging, and chronic conditions. Bone health issues should be included in all major national surveys and health goals (e.g., NHANES, CDC Healthy People goals).

Data about bone disease should be collected to evaluate its prevalence and incidence. These data could be collected about different variables using mechanisms such as:

- Pharmaceutical prescriptions written for osteoporosis prevention and treatment medications (tracked by industry or pharmaceutical companies)
- Number of DXA tests completed each year (in Medicare)
- Calcium and Vitamin D sales (by survey, sales)
- Fracture rates (in Medicare)
- Awareness, knowledge, beliefs, and practices (by public opinion surveys)

### **Evaluate whether existing public education programs work.**

Promising bone health education programs are underway in the public and private sectors. Many nonprofit health organizations sponsor programs. Most programs focus on messages to educate the public about the nature of bone disease and healthy lifestyle measures that can prevent osteoporosis. Some programs target specific age groups, including young women or older adults. Other programs focus on a particular aspect of risk reduction (e.g., fall prevention), while others focus on more general health improvement messages (e.g., healthy diet, exercise). Support for public awareness programs appears to be widespread, as evidenced by the number of states that require public education and outreach programs. In addition, some professional organizations and the pharmaceutical industry sponsor education programs targeting physicians and other health care professionals.

At a minimum, an inventory of programs being conducted by federal and state entities is essential. A starting point might be to work with the CDC, National Chronic Disease Directors, and the National Osteoporosis Foundation to compile such an inventory. One example of such an inventory comes from a 2004 effort by the State of Maryland's Osteoporosis Prevention and Education Task Force, which compiled a directory of state osteoporosis prevention programs and task forces. Any new inventory should include aspects such as social marketing products and ancillary materials, target audiences, key messages and themes, action steps, and the results of any evaluation measures. It also should note any major public policy or legislative measures undertaken that support or promote the measures in the social marketing campaign. For instance, if a social marketing program encourages women to undergo diagnostic screening, legislation should include measures that require insurance coverage for such tests.

Missing from these programs, however, is any real evaluation of what works: which strategies promote behavior change, how widespread that change is, and whether any improvement is seen in the bone health status of target audiences. An evaluation strategy that examines the effectiveness of such programs is needed.

The bone health field also needs to look at what is being done with other chronic diseases to promote awareness of general health and how the messages of bone health might be incorporated in those programs. The evaluation could point to lessons learned from what has been done and what has worked in other chronic disease prevention programs. Successful social marketing campaigns that focus on specific diseases (such as diabetes, breast cancer, substance use, HIV/AIDS, and issues such as traffic safety) as well as on specific populations (e.g., people of color, youth, or men) can serve as models for the field of bone health.



# 4

## Call to Action

Since the 2004 publication of the Surgeon General's report, bone health advocates have attempted to advance the Surgeon General's recommendations. That report was a gift to the bone health field, casting a spotlight on critical issues surrounding bone health and giving advocates a platform from which to launch their important work. It was the starting point for much-needed improvement and change. The report galvanized the community and enabled many advocates to see for the first time how important it was to take a collaborative approach to forging essential advances to enhance education, increase advocacy, and change the treatment paradigm.

Although much has been accomplished, much more remains to be done. An aging America faces a late life of heartbreaking fragility fractures, a red flag that all is not well with the body's most basic system of building blocks and health. Without real, meaningful, and sustained attention to gaps in prevention, diagnosis, and treatment, millions of Americans will bear the physical, emotional, and financial burdens of fragility fractures. The bone health community knows enough to change course to prevent a virtual epidemic of poor bone health. We know what we need to do to improve bone health across the country. Now we need the will, the vision, and the organization to do so.

At no time since the 2004 report release has the field been more ready to drive for progress and improvement. The energy and momentum generated at the Summit for a National Action Plan for Bone Health was inspiring, and this National Action Plan represents the culmination of that force, a force ready to focus on key issues and to make change happen today. The field is called upon to:

- Pool its intelligence, resources, imagination, and ideas to forge a national bone health alliance that can organize many of the activities essential to creating widespread improvement

### Next Steps

1. Produce final report with recommended priorities, lead organizations and timelines – January 2009
2. Establish new work groups and initiatives
3. Ensure long-term implementation of priority programs funded by private and public funds
4. Improve bone health outcomes





- Take a multidisciplinary approach to improvement, by collaborating with leaders of other organizations, specifically those devoted to the prevention and treatment of chronic diseases
- Unite around significant issues that affect access to care as well as the quality of that care

This action plan calls upon the bone health community to **act now** for a better bone health future, for an agenda, and for actions that decrease knowledge gaps and increase knowledge applications. This action plan forms the basis for important next steps for developing and implementing strategies and programs to improve America's bone health. This action plan is being implemented by key stakeholders in the bone health community, who are working together to act on the recommendations presented here. New work groups and initiatives are underway, looking at practical approaches to implementing recommended actions. New initiatives will be undertaken to implement the proposed activities. In short, many groups have heard this call to action and have been spurred to do more now to improve America's bone health.

## National Action Plan for Bone Health: Recommendations from the Bone Health Summit

PRIORITY AREA #1: DEVELOP A BONE HEALTH ALLIANCE		
Strategy	Action Steps	Implementer/ Stakeholders
Forge a national alliance focused on bone health issues	Develop organizational structure <ul style="list-style-type: none"> <li>Determine where the alliance should be housed among the existing bone health organizations</li> <li>Identify and recruit key stakeholder organizations</li> <li>Develop shared vision/mission, charter, and priorities</li> <li>Implement the National Action Plan</li> </ul>	All stakeholders involved in the Bone Coalition
	Move momentum from Bone Health Summit forward <ul style="list-style-type: none"> <li>Sponsor annual national meeting (e.g., “Bone Health Week”)</li> <li>Implement and monitor action plan activities</li> </ul>	
	Work with existing federally focused clearinghouse to coordinate government and non-governmental bone health-related information to: <ul style="list-style-type: none"> <li>Provide online and print resource of all materials available to the field and the public</li> <li>Track and evaluate programs and policies</li> <li>Form the basis for advocacy for research funding and improvement in public policy</li> </ul>	
	Strategically develop social marketing for bone health messages <ul style="list-style-type: none"> <li>Inventory existing programs and their effect</li> <li>Develop and evaluate new messages and programs (including those focused on specific populations such as men and people of color)</li> <li>Integrate bone health messages within bone health organizations so that they are uniform and consistent</li> </ul>	
Collaborate with organizations whose messages about healthy lifestyles dovetail with messages about improving bone health	Foster connections with other chronic disease groups <ul style="list-style-type: none"> <li>Inventory existing programs and campaigns supporting similar messages, and highlight successful programs and their sponsors</li> <li>Convene an interdisciplinary medical advisory group to agree on a key set of messages about the benefits of good nutrition and exercise, as well as fall prevention, for bone health</li> <li>Develop effective messages (e.g., for “healthy lifestyles” or “injury prevention”) for an array of audiences</li> <li>Work with partners to develop integrated and coordinated messages and programs, in part by building on current “hooks” such as Vitamin D</li> </ul>	Representatives from other chronic condition organizations with leaders of bone health advocacy, consumers, and professional organizations

## PRIORITY AREA #2: PROMOTE BONE HEALTH AND PREVENT DISEASE

Strategy	Action Steps	Implementer/ Stakeholders
Build capacity of health care providers to focus on bone health across the lifespan	<ul style="list-style-type: none"> <li>• Work with umbrella organizations and leadership of medical organizations to help: <ul style="list-style-type: none"> <li>○ Primary care providers pay close attention to bone health issues and emphasize the basics of good bone health during interactions with patients</li> <li>○ Health care professionals in emergency departments and orthopedic practices view bone fractures as a sentinel event and refer patients to appropriate resources</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Leaders at schools of medicine and nursing, as well as allied health professional educational programs</li> <li>• Professional societies</li> <li>• Health care professionals</li> </ul>
Promote adequate vitamin D and calcium intake, with a focus on revising the adequate intake level for vitamin D	<ul style="list-style-type: none"> <li>• Continue to test patients at risk for deficiency and prescribe appropriate therapeutic doses of vitamin D for those who are deficient</li> <li>• Enhance provider and patient education and information concerning vitamin D (e.g., what it is, how to raise it with providers and patients, etc.)</li> </ul>	<ul style="list-style-type: none"> <li>• Bone health experts</li> <li>• Researchers and scientists, academicians</li> <li>• Professional and voluntary organizations</li> <li>• Policymakers</li> </ul>
	<ul style="list-style-type: none"> <li>• Join other organizations in their call for the government to review vitamin D supplement standards</li> <li>• Assist in developing consistent messages and recommendations regarding vitamin D intake</li> </ul>	
Increase advocacy activities at the federal and state levels	<ul style="list-style-type: none"> <li>• Review and revise model state legislation (e.g., addressing insurance coverage for screening and prevention)</li> <li>• Collaborate with other organizations on “Capitol Hill Days” with patients and health care professionals</li> <li>• Focus advocacy efforts on topics where there is consensus in the bone health community (e.g., restoring DXA reimbursement rates, providing coverage for evidence-based treatment, increasing research funding, creating a comprehensive program for osteoporosis and other bone diseases within CDC)</li> <li>• Reach out to all bone health and other chronic disease agencies to make bone health part of their advocacy agenda</li> </ul>	<ul style="list-style-type: none"> <li>• Consumer and voluntary health organizations</li> <li>• Professional societies and organizations</li> <li>• Health care professionals</li> <li>• Policymakers</li> </ul>
Develop standards or guidelines of care and performance measures	<ul style="list-style-type: none"> <li>• Inventory existing standards and guidelines</li> <li>• Develop national consensus</li> <li>• Consider incentives for implementation of standards and guidelines</li> <li>• Develop and implement mechanisms for monitoring use of standards and guidelines, including performance measures</li> </ul>	<ul style="list-style-type: none"> <li>• Professional organizations</li> <li>• Health care purchasers/insurers</li> <li>• Federal agencies</li> </ul>

### PRIORITY AREA #3: IMPROVE DIAGNOSIS AND TREATMENT

Strategy	Action Steps	Implementer/ Stakeholders
Find better ways to diagnose disease and assess risk	<ul style="list-style-type: none"> <li>Continue research to understand who is at risk and how best to initiate treatment</li> <li>Explore implementation of FRAX® as pre-screening tool and match it with prevention and treatment protocols</li> <li>Find other existing tools that can be used for bone health screening</li> <li>Assess effectiveness and develop new tools</li> <li>Use stakeholder meeting (e.g., Bone Health Week) to reach consensus on tools</li> </ul>	<ul style="list-style-type: none"> <li>Government researchers and academicians</li> <li>Clinicians</li> <li>Professional societies</li> <li>Industry researchers</li> <li>Experts on bone health</li> <li>Consumer and professional organizations and societies</li> <li>Policymakers</li> <li>Health care purchasers/insurers</li> </ul>
Address issues of adequate reimbursement for diagnosis and evidence-based treatments	<ul style="list-style-type: none"> <li>Increase consumer understanding of access and quality issues around reimbursement rates</li> <li>Seek more appropriate level of funding for reimbursement of costs to increase patient access and prevent disincentives for use</li> <li>Support existing lobbying efforts</li> </ul>	<ul style="list-style-type: none"> <li>Clinicians and health care professionals</li> <li>Professional societies</li> <li>Consumer advocacy organizations</li> <li>Government researchers and academicians</li> <li>Clinicians</li> <li>Professional societies</li> <li>Industry researchers</li> <li>Experts on bone health</li> <li>Consumer organizations and societies</li> <li>Policymakers</li> <li>Health care purchasers/insurers</li> </ul>
Focus on fracture as a sentinel event in bone health management	<div>Focus on professional education</div> <ul style="list-style-type: none"> <li>Develop bone health curricula for medical and nursing schools</li> <li>Include bone health as an element in licensing and credentialing programs, and certification and recertification processes</li> </ul> <div>Research and develop collaborative models of care</div> <ul style="list-style-type: none"> <li>Case managers to identify and work with patients and families, refer for diagnosis and treatment, and monitor compliance</li> <li>Multi-faceted interventions (e.g., telephone-based education for patients and clinical guidelines for providers)</li> <li>Multidisciplinary “Bone Health Teams” to monitor patient progress, encourage BMD testing, and make appropriate treatment recommendations</li> </ul>	<ul style="list-style-type: none"> <li>Clinicians and health care professionals</li> <li>Professional societies</li> <li>Consumer advocacy organizations</li> </ul>



#### PRIORITY AREA #4: ENHANCE RESEARCH, SURVEILLANCE, AND EVALUATION

Strategy	Action Steps	Implementer/ Stakeholders
Continue and expand research now underway, and find ways to make more effective use of existing research	<ul style="list-style-type: none"> <li>Continue research at all levels (i.e., basic, clinical and translational research)</li> <li>Translate findings and developments to the field for application to treatment and care</li> <li>Conduct research to understand how clinical and pharmaceutical research translates into the community setting</li> <li>Conduct research to learn more about racial, socioeconomic, and gender differences in bone health and disease</li> </ul>	<ul style="list-style-type: none"> <li>Federal agencies charged with basic research</li> <li>Industry researchers</li> <li>Policymakers who influence funding</li> <li>Academicians and other researchers</li> </ul>
Collect and analyze data to better understand who is at risk and improve prevention, diagnosis, and treatment	Identify gaps and opportunities in current data collection, reporting and evaluation <ul style="list-style-type: none"> <li>Analyze existing data</li> <li>Conduct gap analysis</li> </ul>	<ul style="list-style-type: none"> <li>Professional and voluntary health organizations that sponsor social marketing programs, in tandem with groups that evaluate and study such programs</li> <li>Federal agencies charged with basic research</li> <li>Industry researchers</li> <li>Policymakers who influence funding</li> </ul>
	Utilize surveys to collect data <ul style="list-style-type: none"> <li>Continue to include existing questions about bone health in federal and private surveys</li> <li>Support efforts to include bone health issues in all major national surveys and national goals related to health and well-being (e.g., NHANES, CDC Healthy People 2020 goals, etc.)</li> <li>Develop new questions to address emerging issues and research questions</li> </ul>	
	Collect baseline data through available mechanisms – for example: <ul style="list-style-type: none"> <li>Pharmaceutical prescriptions written for osteoporosis prevention and treatment medications (tracked by industry or pharmaceutical companies)</li> <li>Number of DXA tests completed each year (Medicare)</li> <li>Vitamin D and calcium sales (by survey or by sales)</li> <li>Fracture rates (Medicare)</li> <li>Awareness, knowledge, beliefs, and practices (public opinion surveys)</li> </ul>	
Evaluate whether existing public education programs work	Inventory of public education programs conducted at all levels <ul style="list-style-type: none"> <li>Coordinate with the National Chronic Disease Directors and the National Osteoporosis Foundation</li> <li>Include aspects such as social marketing products and ancillary materials, target audiences, key messages and themes, action steps, and the results of any evaluation measures</li> <li>Include any major public policy or legislative measures undertaken that would support or promote the measures in the social marketing campaign</li> <li>Conduct evaluations of existing programs to determine what works</li> </ul>	<ul style="list-style-type: none"> <li>Federal agencies</li> <li>Academicians and other researchers</li> </ul>
	Examine effective models used for other chronic conditions (e.g., diabetes, breast cancer, substance use, HIV/AIDS) specific populations (e.g. people of color, men), and specific behaviors (e.g., injury prevention) <ul style="list-style-type: none"> <li>Adapt for use with bone health</li> <li>Work with partners to highlight effective strategies</li> </ul>	



## Appendices

**A. Bone Health Summit Agenda**

**B. Bone Health Summit Planning Committee**

**C. Bone Health Summit Sponsors**

**D. Bone Health Summit Participant List**

**E. Resources: Bone Health Prevention and Education Programs**

## **Appendix A.**

### **Bone Health Summit Agenda**





## Summit for a National Action Plan for Bone Health Washington Court Hotel, Washington, D.C.

**June 26 – 27, 2008**

### Summit Objectives

- Develop a national action plan to increase awareness by the public and health care professionals on the prevention, diagnosis and treatment of osteoporosis and related bone diseases
- Establish priorities for policies and programs for health care professionals, health systems and population-based approaches to promote bone health
- Engage key stakeholders to take action on priorities established at this Summit
- Initiate a long-term implementation and evaluation effort that will be coordinated by a planning group of public and private organizations

## Thursday, June 26

### Welcome Comments

**7:00 a.m.**      **Registration and Continental Breakfast**

**8:00 a.m.**      *Presentation by the Acting Surgeon General on “A Vision for the Future: A Framework for Action to Promote Bone Health” from the Surgeon General’s report. Greetings and historical perspectives from others.*

**Introduction:**   **Ann L. Elderkin, P.A., American Society for Bone and Mineral Research**

**Acting Surgeon General RADM Steven K. Galson, M.D., M.P.H.**

**Congressman Patrick J. Kennedy (D-RI)**

**Stephen I. Katz, M.D., National Institute for Arthritis, Musculoskeletal and Skin Diseases**

**Panel I      What Has Been Accomplished in Bone Health Since the 2004 Surgeon General's Report? What Are the Gaps?**

**8:45 a.m.      Introduction:    Leo Schargorodski, National Osteoporosis Foundation  
Moderator:      Susan Dentzer, Health Affairs**

**Building the Science Base and Changing the Paradigm of Preventing and Treating Fractures**

*Presentations on scientific and clinical practice advances in the prevention and treatment of fractures.*

**Lawrence G. Raisz, M.D., University of Connecticut Health Center  
Joan A. McGowan, Ph.D., National Institute of Arthritis, Musculoskeletal and Skin Diseases**

**9:10 a.m.      Increasing Awareness and Integrating Health Messages on Prevention and Treatment**

*Presentations on challenges in increasing awareness of how osteoporosis and related bone diseases can be prevented and treated, and in integrating health messages on physical activity and nutrition relating to other chronic diseases.*

**Ethel S. Siris, M.D., Columbia University  
Susan Dentzer, Health Affairs**

**9:30 a.m.      Discussion**

**10:00 a.m.      Break**

**Panel II      What Can Health Professionals, Health Systems and Population-Based Approaches Do in Partnership to Promote Bone Health?**

**10:20 a.m.      Introduction:    Charlene Waldman, The Paget Foundation  
Moderator:      Allan S. Noonan, M.D., M.P.H., Morgan State University School of Community Health and Policy**

**Lessons Learned from European and Canadian Action Plans and Policies for Bone Health**

*Presentations on the European action plan for a Europe free from fragility fractures and the Canadian policies and funding of public health programs to prevent and treat osteoporosis.*

**Juliet Compston, M.D., European Union Consultation Panel  
Julie M. Foley, Osteoporosis Canada**



- 10:45 a.m. Opportunities for Intervention**  
*Presentations on opportunities for evidence-based primary, secondary and tertiary prevention interventions for target populations in systems-based and population-based approaches to bone health.*
- Daniel H. Solomon, M.D., M.P.H., Harvard Medical School**  
**John Robitscher, M.P.H., National Association of Chronic Disease Directors**
- 11:05 a.m. Assessment of Progress**  
*Presentations on current methods for epidemiologic surveillance, quality of care outcome measures and other evaluation methods and opportunities, including the status of Healthy People 2010 goals and potential new goals and objectives for Healthy People 2020.*
- RADM Penelope Slade Royall, P.T., M.S.W., Office of Disease Prevention and Health Promotion, U.S. Department of Health and Human Services**  
**Robert A. Adler, M.D., Virginia Commonwealth University School of Medicine**
- 11:25 a.m. Current Resources and Key Stakeholders**  
*Presentation on the roles of key stakeholders and resources including health care professionals, health systems, health care purchasers, communities and community-based organizations, government, voluntary health organizations, professional associations, academic institutions, industry, individuals and families.*
- Allan S. Noonan, M.D., M.P.H., Morgan State University School of Community Health and Policy**
- 11:35 a.m. Living with Bone Disease and Taking Action**  
*Presentations from individuals living with osteoporosis and Paget's disease.*
- Patricia Lear, Living with Osteoporosis**  
**Linda Silfee, Living with Paget's Disease**
- 11:45 a.m. Discussion**
- 12:15 p.m. Charge to the Work Groups**  
*Presentation on the expectations for the work groups for Day 1 and Day 2 to develop strategies for addressing bone health priorities. Participants will be assigned to different work groups for Day 1 and Day 2.*
- Jamie Hart, Ph.D., M.P.H., Altarum Institute**
- 12:25 p.m. Session Concludes**

## Cross-Disciplinary Work Group Session

- 12:45 p.m.**      **Work Group Session and Lunch**  
*Cross-disciplinary work groups meet with facilitators over boxed lunches to develop strategies for addressing bone health priorities.*
- 2:30 p.m.**      **Break**
- 2:50 p.m.**      **Work Group Session**  
*Work groups continue discussions.*
- 5:00 p.m.**      **Adjourn for Day**

## Evening Reception

- 6:00 p.m.**      **Reception**  
*Participants will have the opportunity to network over light hors d'oeuvres.*

## Friday, June 27

### Morning Briefing

- 7:00 a.m.**      **Continental Breakfast**
- 8:00 a.m.**      **Introduction: Tracy Hart, Osteogenesis Imperfecta Foundation**  
**Moderator: Caswell A. Evans, Jr., D.D.S., M.P.H., University of Illinois at Chicago College of Dentistry**
- The Power of Partnerships**  
*Presentations on how partnerships between and among stakeholder groups can be structured to implement the National Action Plan, with examples of effective partnerships for other chronic disease prevention collaborations.*
- Amy B. Slonim, Ph.D., Centers for Disease Control and Prevention (CDC)**  
**Healthy Aging Program-AARP**  
**Caswell Evans, Jr., D.D.S., M.P.H., University of Illinois at Chicago College of Dentistry**
- 8:25 a.m.**      **Living with Bone Disease and Taking Action**  
*Presentations from individuals living with osteogenesis imperfecta and other rare bone diseases.*
- Jamie Kendall, Living with Osteogenesis Imperfecta**  
**Charles Harles, Living with a Rare Bone Disease**
- 8:35 a.m.**      **Discussion**

**9:05 a.m.**      **Turning Strategies to Action**  
*Summary presentations on strategies developed by cross-disciplinary work groups on Day 1 to address bone health priorities. Presentation on expectations for stakeholder-specific work groups on Day 2 to develop strategies and action steps for their specific stakeholder group.*

**Jamie Hart, Ph.D., M.P.H., Altarum Institute**

**9:30 a.m.**      **Session Concludes**

### **Stakeholder-Specific Work Group Session**

**9:40 a.m.**      **Work Group Session**  
*Stakeholder-specific work groups meet with facilitators to develop strategies and action steps for their specific stakeholder group.*

**10:40 a.m.**      **Break**

**11:00 a.m.**      **Work Group Session and Lunch**  
*Work groups continue discussions over boxed lunches.*

**1:00 p.m.**      **Work Groups Conclude**

### **Preparing to Take Action**

**Moderators:**    **Ann L. Elderkin, P.A., American Society for Bone and Mineral Research**  
                         **Leo Schargorodski, National Osteoporosis Foundation**

**1:30 p.m.**      **Discussion of Work Group Strategies and Action Steps**

**2:30 p.m.**      **General Discussion and Next Steps**

**3:30 p.m.**      **Adjourn**

## **Appendix B. Bone Health Summit Planning Committee**

- \*Ann L. Elderkin, Doug Fesler, American Society for Bone and Mineral Research
- Leo Schargorodski, Roberta Biegel, National Osteoporosis Foundation
- Tracy Hart, Osteogenesis Imperfecta Foundation
- Charlene Waldman, The Paget Foundation
- Mara Krause Donohue, Association of State and Territorial Health Officials
- Pam Ford, Osteoporosis Council, National Association of Directors of Chronic Disease Programs
- Toby King, U.S. Bone and Joint Decade
- \*Allan S. Noonan, MD, MPH, Dean, Morgan State University School of Public Health
- \*Lawrence G. Raisz, MD, University of Connecticut Health Center
- Michael Rosenblatt, MD, Dean, Tufts University School of Medicine

## **Federal Advisors**

- \*Joan A. McGowan, Ph.D., NIAMS
- Shilpa H. Amin, M.D., M.Bsc., FAAFP, AHRQ
- Yvonne Green, CDC

*\*Editors of Surgeon General Report*

## **Appendix C. Bone Health Summit Sponsors**

- The Alliance for Better Bone Health (P&G Pharmaceuticals, sanofi-aventis)
- Amgen
- BIO-Biotechnology Industry Organization
- Eli Lilly and Company
- Novartis
- Wyeth

## Appendix D.

### Bone Health Summit Participant List

Organization	Name
Adult Women's Health Alliance	Morris Notelovitz, MD, PhD
Agency for Healthcare Research and Quality (AHRQ)	Shilpa Amin, MD, MBSc, FAAFP
Agency for Health Research and Quality (AHRQ)	Shakeh Kaftarian, PhD
American Academy of Orthopaedic Surgeons	E Anthony Rankin, MD
American Academy of Pediatrics	Bernard David Horn, MD
American Academy of Physician Assistants	Paul S. Robinson, PA-C
American Association of Clinical Endocrinologists	Steven Petak, MD, JD
American Association of Occupational Health Nurses	Richard Kowalski, RN MSA, COHN-S
American College of Physicians	F Michael Gloth, III, MD
American Geriatrics Society	Silvina Levis, MD
American Orthopaedic Association	Douglas Dirschl, MD
American Orthopaedic Association	Kristin Olds Glavin, JD
American Orthopaedic Association	Sharon Popielewski
American Academy of Physical Medicine & Rehabilitation	Patricia Graham, MD
American Physical Therapy Association	Anita Bemis-Dougherty, PT, DPT, HAS
American Society for Bone and Mineral Research	Maria Luisa Brandi, MD, PhD
American Society for Bone and Mineral Research	Robert Civitelli, MD
American Society for Bone and Mineral Research	Ann Elderkin, PA
American Society for Bone and Mineral Research	Doug Fesler
American Society for Bone and Mineral Research	Mark Johnson, PhD
American Society for Bone and Mineral Research	Barbara Kream, PhD
American Society for Bone and Mineral Research	Meryl LeBoff, MD
American Society for Bone and Mineral Research	Janet Rubin, MD
Amgen	Neil Bair
Amgen	Kerry Beth Daly
Amgen	Helen Torley
Amgen	Stewart A. Turner
Amgen	Valerie Volpe
Association of State and Territorial Health Officials	Mara Krause Donahue
California Hispanic Osteoporosis Foundation (CHOF)	Alberto Focil, MD
Cavarocchi Ruscio Dennis Associates	Joyce Briscoe
CDC/National Center Health Statistics	Ann Looker, PhD
Centers for Disease Control and Prevention	Yvonne Green
Centers for Disease Control and Prevention	Amy B. Slonim, PhD



<b>Children's National Medical Center</b>	Laura Tosi, MD
<b>Council of Musculoskeletal Educators</b>	George Lawry, MD
<b>DHHS Office on Women's Health</b>	Jonelle Rowe, MD
<b>DHHS Office on Women's Health</b>	Calvin Teel, MS
<b>Eli Lilly and Company</b>	Maria Rivas, MD
<b>European Union Consultation Panel</b>	Juliet Compston, MD
<b>FDA Office of Women's Health</b>	Susana Perry
<b>Fibrous Dysplasia Foundation</b>	Charles Harles
<b>Foundation for Osteoporosis Research and Education</b>	Kathleen Cody
<b>GlaxoSmithKline</b>	Lisa Behrens
<b>GSK Consumer Healthcare</b>	Adrianne Bendich, PhD
<b>Harvard Medical School</b>	Daniel Solomon, MD, MPH
<b>Health Affairs</b>	Susan Dentzer
<b>Hologic</b>	John Jenkins
<b>Hologic</b>	Kim McKillips, RN, MSN
<b>International Osteopetrosis Association</b>	Ashley Gettinger
<b>International Osteopetrosis Association</b>	Beth Miller
<b>International Society for Clinical Densitometry</b>	Andrew Laster, MD
<b>International Society for Clinical Densitometry</b>	Priscilla Shisler
<b>Kennedy Krieger Institute</b>	Jay Shapiro, MD
<b>Kentucky Department for Public Health</b>	Angela Deokar
<b>Kyphon (kyphoplasty)</b>	Debbie M. Lin
<b>Lymphangiomatosis and Gorham's Disease Alliance</b>	Jack Kelly
<b>Minnesota Department of Health</b>	Pam York, PhD, RD
<b>Morgan State University School of Public Health</b>	Allan S. Noonan, MD, MPH
<b>National Aeronautics and Space Administration (NASA)</b>	Saralyn Mark, MD
<b>National Association of Chronic Disease Directors</b>	Kathleen O'Connor, RN, MS
<b>National Association of Chronic Disease Directors</b>	John Robitscher, MPH
<b>National Association of Chronic Disease Directors</b>	Betty Wiser, Ed.D, MS
<b>National Association of Commissions for Women</b>	Ramona Fullman
<b>National Association of State Units on Aging</b>	Martha Roherty
<b>National Dairy Council</b>	Lisa A. Spence, PhD, RD
<b>National Hispanic Medical Association</b>	Elena Rios, MD, MSPH
<b>National Institute for Arthritis, Musculoskeletal and Skin Diseases</b>	Janet Austin
<b>National Institute for Arthritis, Musculoskeletal and Skin Diseases</b>	Branden Brough, PhD

<b>National Institute for Arthritis, Musculoskeletal and Skin Diseases</b>	Jonelle Drugan, PhD, MPH
<b>National Institute for Arthritis, Musculoskeletal and Skin Diseases</b>	Stephen I. Katz, MD, PhD
<b>National Institute for Arthritis, Musculoskeletal and Skin Diseases</b>	Melanie Martinez, MPA, CHES
<b>National Institute for Arthritis, Musculoskeletal and Skin Diseases</b>	Joan McGowan, PhD
<b>National Institute for Arthritis, Musculoskeletal and Skin Diseases</b>	Wilma Peterman Cross, MS
<b>National Institute for Arthritis, Musculoskeletal and Skin Diseases</b>	Trish Reynolds, RN, MS
<b>National Institute for Dental and Craniofacial Research</b>	Patricia Sheridan
<b>National Institutes of Diabetes, and Digestive and Kidney Diseases, National Institutes of Health</b>	Saul Malozowski, MD, PhD, MBA
<b>National Medical Association</b>	Byron Sogie-Thomas, MS
<b>National Osteoporosis Foundation</b>	Roberta Biegel
<b>National Osteoporosis Foundation</b>	Molly Carey
<b>National Osteoporosis Foundation</b>	Piper Dankworth
<b>National Osteoporosis Foundation</b>	Teresa Dyer
<b>National Osteoporosis Foundation</b>	Robert F. Gagel, MD
<b>National Osteoporosis Foundation</b>	Deborah T. Gold, PhD
<b>National Osteoporosis Foundation</b>	Judith Hulka
<b>National Osteoporosis Foundation</b>	C Conrad Johnston, MD
<b>National Osteoporosis Foundation</b>	Joan Nicholaysen
<b>National Osteoporosis Foundation</b>	Rita Norton
<b>National Osteoporosis Foundation</b>	Susan Randall, RN, MSN, FNP-BC
<b>National Osteoporosis Foundation</b>	Paul G. Rogers
<b>National Osteoporosis Foundation</b>	Leo Schargorodski
<b>National Osteoporosis Foundation</b>	Ethel Siris, MD
<b>National Osteoporosis Foundation</b>	Judith Thomas
<b>National Osteoporosis Foundation</b>	Susan Whittier
<b>National Women's Health Resource Center</b>	Marisa Rainsberger
<b>North American Menopause Society</b>	Wulf Utian, MD, PhD
<b>Northwestern University Feinberg School of Medicine</b>	Andrew Bunta, MD
<b>Novartis Pharmaceuticals Corporation</b>	Peg McCormick
<b>Novartis Pharmaceuticals Corporation</b>	Gregory Slyfield
<b>Novartis Pharmaceuticals Corporation</b>	Mona Wahba, MD
<b>Nurse Practitioners in Women's Health</b>	Susan Wysocki, RNC, NP, FAANP

<b>Office of Disease Prevention and Health Promotion, DHHS</b>	RADM Penelope Slade Royall, PT, MSW
<b>Office of Women's Health</b>	Wanda Jones
<b>Osteogenesis Imperfecta Foundation</b>	Ken Finkel
<b>Osteogenesis Imperfecta Foundation</b>	Tracy Hart
<b>Osteogenesis Imperfecta Foundation</b>	Mary Beth Huber
<b>Osteoporosis Canada</b>	Julie Foley
<b>Osteoporosis Canada</b>	Elizabeth Stanton
<b>Paget Foundation</b>	Henry Bone, MD
<b>Paget Foundation</b>	Arthur Chausmer, MD, PhD
<b>Paget Foundation</b>	Charlene Waldman
<b>Paget Foundation</b>	Stanley Wallach, MD
<b>Pennsylvania Department of Health</b>	Becky Kisbaugh
<b>Procter and Gamble</b>	Allison King, PhD
<b>Procter and Gamble</b>	Andrea B. Klemes, DO, FACE
<b>Procter and Gamble</b>	Shannon Penberthy, MBA
<b>Procter and Gamble</b>	Dave Valent
<b>Roche Diagnostics</b>	Michael Samoszuk
<b>Ruth Jackson Orthopedic Society</b>	Kim Templeton, MD
<b>Society for Women's Health Research</b>	Phyllis Greenberger, MSW
<b>University of Connecticut Health Center</b>	Lawrence Raisz, MD
<b>University of Illinois at Chicago College of Dentistry</b>	Caswell A. Evans, Jr., DDS, MPH
<b>US Bone and Joint Decade</b>	Toby King
<b>US Bone and Joint Decade</b>	Nancy Lane, MD
<b>US States Bone and Joint Decade</b>	J. Edward Puzas, PhD
<b>United States Congress</b>	Patrick J. Kennedy (D-RI)
<b>United States Department of Health and Human Services</b>	RADM Steven K. Galson, MD, PhD
<b>Virginia Commonwealth University School of Medicine</b>	Robert A. Adler, MD
<b>Women in Government</b>	Sarah Gonzales
<b>Wyeth Pharmaceuticals</b>	Arkadi Chines, MD
<b>Wyeth Pharmaceuticals</b>	Carol Jane
<b>Wyeth Pharmaceuticals</b>	Gerard Schmitt
<b>Wyeth Pharmaceuticals</b>	Edward Trott, MD
<b>Patient</b>	Jamie Kendall
<b>Patient</b>	Patricia Lear
<b>Patient</b>	Linda Silfee

## Bone Health Summit Facilitators

<b>Gold Cottage Industries</b>	Donna Aligata
<b>Altarum Institute</b>	Jodi Anthony, MPH
<b>Altarum Institute</b>	Chris Botsko, MPH
<b>HomeBase, the Center for Common Concerns</b>	Marty Fleetwood, JD
<b>Altarum Institute</b>	Jamie Hart, PhD, MPH
<b>Altarum Institute</b>	Antigone Hodgins, MEd
<b>TeamWorks</b>	Suganya Sockalingam, PhD

<b>Altarum Institute Staff</b>	Sally Holthouse
	Zena Itani, MPH
	Sheryl Mathis, MPH
	Sam Perryman
	Janice Schuster
	Sandra Silva, MPP
	Laura Sternesky McGovern, MPA
	Kelly Stevens
	Naomi Tein, MPH
	Kenan Zamore

## **Appendix E. Resources: Bone Health Prevention and Education Programs**

### **American Academy of Family Physicians**

<http://search.aafp.org/search>

### **American College of Physicians**

[www.acponline.org](http://www.acponline.org)

### **Agency for Healthcare Research and Quality**

[www.ahrq.gov](http://www.ahrq.gov) and <http://www.ahrq.gov/downloads/pub/evidence/pdf/vitamind/vitad.pdf>

### **American Society for Bone and Mineral Research**

[www.asbmr.org](http://www.asbmr.org)

### **Bone Health and Osteoporosis: A Report of the Surgeon General**

[www.surgeongeneral.gov/library/bonehealth](http://www.surgeongeneral.gov/library/bonehealth)

### **Centers for Disease Control and Prevention: Bone Health**

[www.cdc.gov/nccdphp/dnpa/nutrition/nutrition\\_for\\_everyone/](http://www.cdc.gov/nccdphp/dnpa/nutrition/nutrition_for_everyone/)

### **International Osteoporosis Foundation**

[www.iofbonehealth.org](http://www.iofbonehealth.org)

### **National Coalition for Osteoporosis and Related Bone Disease**

[www.asbmr.org/images/pdf/BCFactSheet07.pdf](http://www.asbmr.org/images/pdf/BCFactSheet07.pdf)

### **National Health Council**

[www.nationalhealthcouncil.org](http://www.nationalhealthcouncil.org)

### **National Institutes of Health, National Institute of Arthritis Musculoskeletal and Skin Diseases: Senior Health**

<http://nihseniorhealth.gov/osteoporosis/toc.html>

### **National Institutes of Health, Osteoporosis and Related Bone National Resource Center**

[www.niams.nih.gov/Health\\_Info/](http://www.niams.nih.gov/Health_Info/)

### **National Osteoporosis Foundation**

[www.nof.org](http://www.nof.org)

### **Osteogenesis Imperfecta Foundation**

[www.oif.org/site/PageServer](http://www.oif.org/site/PageServer)

### **The Paget Foundation**

[www.paget.org](http://www.paget.org)

### **United States Bone and Joint Decade**

[www.usbjd.org](http://www.usbjd.org)

### **United States Department of Health and Human Services**

[www.healthfinder.gov](http://www.healthfinder.gov)

### **United States Preventive Task Force: Guide to Clinical Preventive Health services, 2008**

<http://www.ahrq.gov/clinic/USpstfix.htm>



# Endnotes

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